

Appendix B

Palliative care services

Independent review - full report

*Review of provision in Kensington & Chelsea,
Hammersmith & Fulham and Westminster*

Penny Hansford - June 2019

Preface

This was a complex review to carry out. Dying is not something most of us think about until it touches us personally. When it does, it often evokes strong and sometimes unfamiliar feelings. The health and social care professionals that I have met in the course of this review also had strong feelings and a desire to deliver the very best of care to dying people and their families. The clinical reference group that worked with me on this review also demonstrated a desire to get the system of support for dying people more equitable and more co-ordinated than it is at present. I am grateful to their support, challenge and robust discussion. Thank you to the many who submitted evidence, particularly bereaved carers who took the trouble to ‘tell their stories’ which for some will have been hard. These are the voices to which we must listen.

I am also grateful the group within the CCG’s that have supported this review. Benjamin Smith, Project Manager, Central London CCG, Lena Coupland ,Delivery Manager for Integrated Care, NHS West London CCG , Ray Boateng, Head of Integrated Commissioning and Continuing Care , Joint Commissioning Team and Sarah Flynn, Communications officer, NW London CCGs.

With thanks to the Clinical Steering Group

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Background & rationale

Central London Clinical Commissioning Group (CCG), West London CCG and Hammersmith & Fulham CCG (the tri-borough) commission their palliative care services together for the boroughs of City of Westminster (WCC), the Royal Borough of Kensington & Chelsea (RBKC) and the London Borough of Hammersmith & Fulham (LBHF).

Current provision is commissioned via three contracts. Two are with independent charitable hospices, St Johns Hospice (SJH) and Royal Trinity Hospice (RTH) and one is with an NHS provider, the Central London Healthcare Trust (CLCH) who delivers services at The Pembridge Hospice (PH). There is also a community service provided by Central and North West London NHS Foundation Trust (CNWL), for patients in North East Westminster. This is a small part of a larger service which provides care to South Camden, Islington, UCLH and HCA and commissioned by Camden CCG.

Context of the review

On October 1st 2018, the inpatient beds at the PH were suspended, as there was inadequate medical cover for the inpatient unit. A consultant registered on the specialist register for palliative care is required to cover inpatient care. This event, combined with commissioners desire to ensure palliative care services are fit for the future, meant the tri-borough CCGs decided to review the current provision of specialist palliative care.

Central London CCG, on behalf of West London CCG and Hammersmith & Fulham CCG, commissioned Penny Hansford, former Director of Nursing at St Christopher's Hospice, South East London; as the independent reviewer in November 2018. A 'Call for Evidence' was launched on 14 December 2018 and a clinical steering group was created, with representatives from GPs, acute trusts, community trusts and hospice providers, all with an interest in specialist palliative care.

Timeline

The process for the review followed this timeline:

Event	Date
Suspension of inpatient admissions to the PH	1 st October 2018
Penny Hansford commissioned to review palliative care services within the tri-borough CCGs	26 th November 2018
First clinical steering group held	29 th November 2018
Call for evidence launched	14 th December 2018
Engagement with providers, stakeholders and patient groups	1 st December-14 February 2019
Call for evidence closed	14 February 2019
Publishing of review	14 June 2019

Figure 1: Timeline of palliative care review

The review was launched on the 26th November 2018 and concluded on February 28th 2019. The review included extensive consultation with health and social care professionals, and a public and patient consultation via available communication channels, the media and patient/public engagement groups (see appendix A). A literature review was undertaken of key national policies and recent research evidence was included, to ensure that any recommendations were evidence based.

The review also looked at a number of new models of palliative and end of life care being developed in the UK aimed at improving inequalities in access and to modernise services. All of the recommendations are included in this report and summarised in the Executive Summary.

Defining specialist palliative care

This strategic review of ‘specialist’ palliative care services has caused some confusion in terminology.

Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Traditionally, services called ‘specialist’ as opposed to ‘palliative care’ services, which has included hospices, would define themselves as caring for people with the most complex physical and psychological symptoms. However, given there is no standard definition of ‘complexity’ it is not possible to distinguish in any standardised way those people who need specialist input. Furthermore, the needs of a patient and family are not linear and most people will have episodes or situations where review and advice will need to be sought from the experts who specialise in palliative care.

This review concentrates on the ‘specialist’ palliative care services delivered by SJH, RTH, PH and the CNWL service. However, as palliative care is ‘cross cutting’ the review has needed to consider how

the wider system works together with community nursing, primary and social care. All of whom are also delivering palliative care as part of, rather than the entirety of their role. The term 'specialist palliative care' and 'palliative care' are used interchangeably in this report.

Statistics - End of life in the boroughs

The boroughs

- The total population of the tri-borough CCGs is 583,525. (Hammersmith & Fulham 182,998, Westminster 244,786 and Kensington & Chelsea 155,741) (2017)¹
- The average number of deaths per year in the tri-borough is 2,815 between 2014-2017. In 2017-18 there were 2,777 deaths.²
- Of these 2,222 are said to be 'expected' deaths.
- On average there are 844 (30%) deaths per year due to cancer, 768 (27%) due to circulatory disease, 341 (12%) deaths due to respiratory disease and 863 (31%) deaths due to other causes.³
- In England there was a 1.6% rise in deaths since last year and this is expected to rise by 10% by 2030. However, in the tri-borough the number of deaths is not expected to significantly rise, therefore no recommendations have been made specifically about forecasted capacity for the next three years.
- The population of over 65's is projected to grow by 20.4% in England over the next 10 years. However, the tri-borough has a lower than average population of over 65- year olds compared to 16.3% for England. (RBKC 13.6%, WCC 10.6% and LBHF 10.3%) The predicted rise of this age group is negligible with only LBHF predicting a 6.7% rise in the ten-year period.⁴
- Almost two thirds of deaths occur in the over 75 age group in the tri -boroughs, which mirrors the national picture.
- Care home provision across the three boroughs is among the lowest in England 3.1 beds per 100 of the population over 65, compared to 4.3 for London and 4.9 for England. (appendix B)

Place of Death (Appendix C)⁵

- Deaths by percentage in care homes is also correspondingly low 11.9% compared to 14.3% for London and 21.8% for England.
- The percentage of deaths at home is significantly higher in all three boroughs (28.2%) than the England average (23.5%) and the London average (23.8%) in LBHF (28%), WCC (29%) and RBKC (27.6%).
- The percentage of deaths in a hospice is slightly higher (7.7%) than the average for England 5.7% and the region 6.6%. 213 people from the tri boroughs died in a hospice in 2017-8.
- Deaths in hospital (48.9) are slightly higher than England (46.9) but below the London average (52.8%).
- A person in their last year of life with cancer can expect 3.49 admissions and use 18.25 bed days. With non-cancer conditions this is 3.01 admissions and use 18.45 bed days. The percentage of people who have 3 or more admissions in their last 90 days of life is 7.8% for the tri-boroughs, 9% for the NW London area and 6.9% for England (Appendix D).
- The number of completed 'Co-ordinate my Care' (CMC) care plans for the calendar year 2018 was 788 representing a 35% CMC completion rate (see appendix E). Use of CMC is

important as it guides professionals to a patient’s wishes and preferences, especially in urgent situations.

The Impact on Place of Death when one of the 4 specialist palliative care services are involved

- Home deaths increase by 4.1%
- Hospital deaths are reduced by 23.5%.
- Care home deaths increase by 7.7%.

The literature on place of death

It is often quoted that more than 70% of people would prefer to die at home. In a systematic review looking at peoples preferred place of death, home preference estimates ranged from 31%-87%for patients, 25%-64% for caregivers and 49%-74% for the public. 20% of 1395 patients changed their preferences.⁶ Dying at home is however associated with a greater sense of peace and less intense grief for the bereaved.⁷

Cost of Care

- For every 1000 living people, nine will die within the year and seven of these will have end of life care needs prior to their death and be disproportionately high users of hospital care; consuming an estimated 27% of hospital spend.⁸
- The cost of hospital care for the over 65 age group in their last year of life is £2 in every £10.⁹
- There is also a growing body of evidence that the provision of specialist palliative care services results in improved experience and reduced costs at the end of life. Benefits include doubling a person’s chances of dying at home, reducing patient symptom burden and reducing costs by between 18 and 35 per cent, when compared with usual care.¹⁰

Recommendations for Commissioning Outcomes:

- Decrease the numbers of admissions in the last 90 days of life.
- That more people are supported to die at home or in their care home.
- Increasing the ‘reach’ of the specialist palliative care services to reach 75% of expected deaths either by direct provision or by case management/advising.

Local & national policy on palliative and end of Life Care

There are nine key documents that have been published between 2015 and 2017 that have been used throughout the development of the recommendations found within the review, (appendix F):

- ‘Specialist Palliative Care, Information for Commissioners’ 2016 ¹¹
- ‘Ambitions for Palliative and end of life care’ 2015 ¹²
- Review of Choice in End of Life Care’ 2016¹³
- Commissioning Person Centred End of Life Care: A toolkit for health and social care. 2016¹⁴
- ‘Actions for End of Life care 2014-16’ ¹⁵
- ‘What is important to me-a review of choice in end of life care 2015’¹⁶
- Shifting the Balance of Care-March Nuffield Trust 2017¹⁷
- Independent Review of the Liverpool Care Pathway 2013 ¹⁸
- Introducing the Outcomes Assessment and Complexity and Collaborative Suite of Measures. Kings College London University 2015¹⁹

North West London STP Priorities^{20 21}

The boroughs of RBKC, Hammersmith & Fulham and Westminster sit within the footprint of the North West London Sustainability Transformation Plan (STP). In June 2016 the STP was published; one of the key objectives was to improve the overall quality of end of life care.

In 2015/6 a steering group was formed as part of the NW London STP plan - to improve care in the last phase of life. The recommendations of the group include:

- Implement a 24/7 telemedicine co-ordination, advice and support line for care home staff and their residents.
- Build on St Luke’s Hospice experience of a single point of access co-ordination centre for people at the end of life
- Align GP’s more closely with individual care homes and develop enhanced care services.
- Develop robust and consistent identification of patients in the last phase of life and avoid unplanned admissions work in primary care
- Support specific extensions and adjustments to existing Hospice@Home /rapid response /community pharmacy services.
- Build on schemes such as homeward, STARS, CIUS to avoid acute admissions and support greater co-ordination of health, social and voluntary sector services.
- Develop training and education for GP’s, Care Home and LAS staff.

Some of the above is yet to be implemented. Each CCG within the NW London STP footprint has to mandatory commission a new dedicated care home advisory service, called 111*6. This provides urgent clinical advice for care home staff. A NW London pilot provides an enhanced version of this service, with a dedicated team of advance nurse practitioners who give clinical advice.

A care home manager leadership programme has been commissioned by NW London CCG’s with funding from Health Education England NWL. A NW London care home dash board, initially focusing

on unscheduled hospital service utilisation was created to enable the sharing of intelligence between health and social care, support learning and promote best practice.

Other priorities for palliative and end of life care is to work with commissioners and services to reduce the gap in variation in service delivery and to develop comprehensive standardised data sets and metrics for multiple stakeholders. The STP is clear that palliative and end of life initiatives need to be linked to advanced frailty initiatives and the development of integrated care systems.

Recommendation:

- For the CCG's within the STP footprint, ensure similar models of service provision are standardised and implemented throughout.
- For the CCG's to work towards a lead commissioner for palliative and end of life care in the STP footprint.

JSNA for the Tri-Borough CCGs²²

In 2016, a Joint Strategic Needs Assessment (JSNA) was published but there has been a lack of leadership and structure to implement the recommendations. It has five key recommendations:

- Maximise choice, comfort and control through high quality effective care planning and co-ordination.
- Promote end of life care as everybody's business and develop communities which can help and support people.
- Identify clear strategic leadership for end of life care across both social care, health care and the independent sector.
- Develop a co-ordinated education and training programme for practitioners, the person dying, carers and for family members.

Tri Borough CCG Priorities

The individual CCG's are in the process of setting up integrated care partnerships (ICPs). These are alliances of NHS and other providers that work together to deliver care by agreeing to collaborate rather than compete. These providers include acute hospitals, community services, mental health services and GPs. Social care and independent and third sector providers may also be involved. In the tri-borough CCGs, these are at different stages of development.

Hammersmith & Fulham Integrated Care Partnership have been working together since February 2018. This partnership has three clinical workstream areas of initial focus.

- Proactive prevention and management of frailty.
- Improving the diagnosis of dementia and early advance care planning.
- Improving end of life care, including care homes.

The members of the partnership have signed an alliance agreement to work together which includes the local NHS acute trusts, the community trust, the mental health trust and the GP Federation. The local authorities attend but haven't yet signed the partnership agreement. Hammersmith & Fulham have access to a range of specialist palliative care providers, including the RTH and CLCH who operate their services from PH. CLCH are represented but RTH are not part of the partnership agreement. This leaves part of the hospice sector outside of the developing integration.

West London CCG (which includes the Royal Borough Kensington and Chelsea and the wards of Queens Park and Paddington) has developed its own integrated care strategy 2018 - 2020. The current strategy is an enhancement of the 2015 'My Care My Way' (MCMW) programme. MCMW is targeted at over 65's and provides case management and health and social care navigation. It also funds a programme of support for people with long term mental health problems. 'Community Living Well.' The current strategy aims to deliver a fully integrated community health team serving the whole populations health and social care needs by April 2019. The outcomes are based around the proactive maintenance of good health and disease management. End of Life Care is one component of the programme. A co-design group was established in 2018 to understand the challenges and develop a model for patients. This work has been paused to focus on this review.

The proposed Integrated Care delivery model will be through clusters of GPs working together in five 'Primary Care Networks'. Each Primary Care Network will have an integrated care team built around it. A reorganisation of estates is desired to enable the teams to be co-located. The longer -term vision is to develop a multi-speciality community provider (MCP), a form of accountable care system, meaning that all providers will eventually share a single capitated budget with a co-ordinated model of care.

Westminster

Central to the transformation plans for Central London CCG is their Primary Care Strategy 2017-20. GP's will be promoted as the systems leader and practices will work together in the concept of "village" working within small groups of GP practices, adult social care staff, care co-ordinators and others working together as a multi professional team referred to as a 'primary care home'. Larger more sustainable delivery models in the community between the primary care homes have already been developed. From April 2019 Central London CCG will be creating a new structure, the multi-speciality community provider (MCP) based on the system of accountable care aimed at promoting integration of care services with joint responsibility and accountability – one system, one budget and better outcomes.

Going forward and as these new structures emerge in all three boroughs the specialist palliative care service must integrate into the new models and not sit outside of them. The responsibility and thinking about how this can be implemented sits with both the commissioners and the palliative care providers. The hope of this happening will be helped if, as a result of this palliative care review the numbers of providers are rationalised to two or one lead provider for the community palliative care services.

Recommendations:

- In the planning of the integrated care services and development of primary care, the tri-borough CCGs must ensure that the community level, specialist palliative care service is fully integrated into developing systems, including the concept of co-location.
- Work with the integrated care systems to deliver care to groups that are 'hard to reach' particularly the homeless and those with a learning disability and those with mental health problems.
- To ensure primary care have regular multi professional meetings to review their palliative care patients.
- To standardise models of service provision across the Tri-Borough and NWL footprint.

National Models of End of Life Care²³ (appendix G)

In response to the changing demography and needs of dying people, nationally enhanced models of end of life care are being developed and evaluated. This enhanced care can demonstrate quality improvements and cost savings with reduced emergency admissions, reduced length of hospital stay and increased achievement of choice around place of death. Evidence suggests there are a number of overarching components that are necessary to ensure success. A published report reviewed 66 palliative and end of life care co-ordination systems with the aim of identifying best practice, improving people's experience and choice at the end of life. The components of service models from the report combined with other components from research include the following:

1. Clinical triage 24/7 with a single phone number and the availability for face to face home assessment with a short response times for clinical situations that are urgent. This is paramount as there are often multiple professionals and organisations involved as someone whose death is expected deteriorates, leading to fragmented disorientating experience for patients and families (Ombudsman report 2105).
2. Rapid response mobilisation of health and social care that is able to stay with patients for prolonged periods including overnight.
3. Availability of medication and equipment.
4. Skilled and competent practitioners.
5. Integration with all other service providers in the area, evidence of joined up services with acute care and discharge care.
6. Evidence of electronic record sharing. EPaCCS- for the tri-borough CCGs this means at the very least the formation of a CMC record.
7. The building of strong links with local community groups/ the voluntary sector.
8. Consideration of the needs of hard to reach groups and building links with local communities.

There are three excellent examples of palliative and end of life care co-ordination centres in the London region. All have been developed and run by a hospice service working as the lead organisation but in partnership with others and can be seen in Appendix H.

The provision of Specialist Palliative Care in the tri-borough

The four providers of specialist palliative care in the tri-borough CCGs, are located close together, a unique feature of the geography of London. A small number of non-contracted patient activity, goes to Marie Curie Hospice Hampstead (6 inpatients and 28 outpatients for 2017-8).

According to the 2017 CQC report hospices deliver an extremely high standard of care. 70% are rated as good and 25% are rated as outstanding. This is considerably higher than any other CQC regulated sector where only 6% of NHS acute hospitals' core services and 4% of GP practices were rated as outstanding and, within adult social care, 2% of domiciliary care agencies, nursing homes and residential care homes were rated as outstanding.²⁴

SJH, PH and RTH all received an overall 'good' rating in their most recent CQC reports. The PH were inspected as part of an overall CLCH inspection as a large community provider, SJH as part of the private hospital. Only RTH received a stand-alone inspection.

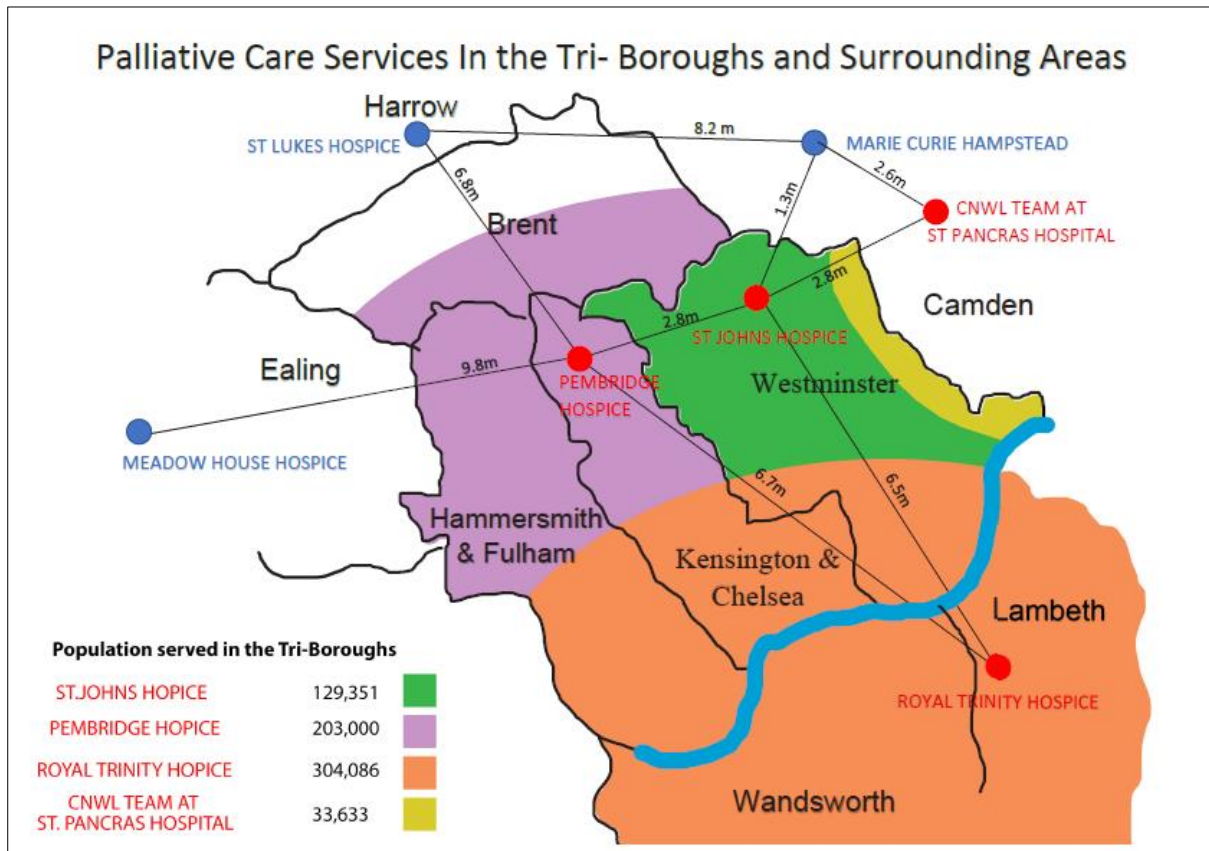
The hospices have significant variations in their service provision particularly in their community services. For example, the SJH finishes at 5pm with advice available from a ward nurse overnight. PH community specialist palliative care nurses also finish at 5pm, but the clinical nurse specialists are available to give telephone advice overnight. At RTH, the CNS's finish at 8pm and are on call until the next morning for telephone advice. At CNWL, they operate a Monday-Friday 9am-5pm visiting service with on call support outside of these hours. At these times advice can be obtained over the telephone and clinical visits provided at weekends or at night if necessary. Contact is made via the hospital switchboard. The ratio of specialist palliative care nurses per head of population also differs.

RTH have a 1:47,000 ratio, PH 1:48,000 and SJH 1:23,000. RTH has one independent nurse prescriber and PH has two and SJH have none.

Although NHS Central London CCG is the lead commissioner for CLCH and the PH, palliative and end of life services are commissioned by the Joint Adults Commissioning team, held by Hammersmith & Fulham CCG. No single CCG is responsible for all palliative and end of life services in Westminster, Kensington & Chelsea and Hammersmith & Fulham.

Both RTH and SJH deliver an in-depth quality analysis of their services to the CCG's. The PH does not. Commissioners stipulate what is required of the providers but some hospices produce quality reports as part of their governance which they share with their commissioner. A community palliative care service, continues to operate in North East Westminster and is provided by CNWL, based at St Pancras Hospital Monday-Friday 9am-5pm. This service is commissioned by Camden CCG.

Figure 2: Location of palliative care services



The Pembridge Hospice

Overview

Pembridge Hospice (PH) is part of Central London Healthcare NHS Trust (CLCH). The Hospice is one of a small number of NHS Hospices in England. CLCH is a large provider of community healthcare managing 78 different services across 11 London boroughs and in Hertfordshire. It employs 3,500 staff. Pembridge Hospice is the only specialist palliative care service in its portfolio.

Workforce

Pembridge Hospice has 69 staff representing 60 full time employees (FTEs) and 45 volunteers. At any one time it supports approximately 400 patients. As part of the CLCH CQC inspection that took place in 2017, the trust which included the PH was rated as 'good' in all domains.

Finance, contract and monitoring

PH is commissioned as part of a block contract. The commissioner has not specified any palliative care key performance indicators in the contract for the service. However, the trust reports to commissioners on the number of admissions, number of community and day care contacts/attendances. Quality of care is reported on a monthly basis to the CCG Quality Group in terms of patient experience and clinical care. As well as the tri-boroughs it also delivers services to Brent CCG.

CLCH operates a registered charity with a number of named funds within the overall CLCH charity. The largest fund is 'The Pembridge Hospice Charity'. The accounts for 2017-8 show a balance in the Pembridge Hospice Charity Fund of £2.069m, which aims to support the entire trust. The Pembridge Hospice Charity funds 4.97 FTE posts. These posts support the wellbeing of patients, families and carers and are not clinical posts. This equates to £187k funding. Additionally the charity provides £50k per year to support patient activities such as a reading service. The total annual charitable contribution of £238k represents 7% of the overall running costs.

Strategic plan and progress

The Trust End of Life Care strategy is a broad strategy and incorporates all end of life services e.g. Community Nursing and the specialist palliative care services provided by the Pembridge. The overarching aims of the End of life Care strategy 2017 to August 2019 are:

- To enable integrated, co-ordinated end of life care.
- To promote the early identification of people at the end of life and delivery of compassionate end of life care by the CLCH workforce and other partners.
- To improve end of life care and experience for patients and their families receiving care from CLCH with advanced, progressive and incurable illness.
- To reduce inequalities, eliminate discrimination and advance equality when developing, arranging and delivering end of life care.
- To improve access to end of life care services, improve the coordination and choice of type and place of care and reduce inequalities of service provision across CLCH.
- To increase the proportion of patients who are cared for and die in their preferred place of care.
- To be aware of the role of the wider community in the dying person and other important networks.

Key achievements to date include:

- The implementation of a patient user group at Pembridge and the Swan Song project ensuring the patients voice is heard and listened to when making changes to the services.
- A revised paper and electronic Individual plan of care.
- The implementation of further training on advanced communication, key documentation and the care and use of syringe drivers.
- Competencies related to end of life care for staff which are now embedded as part of existing development programmes.
- The implementation of an Always Event focused on bereavement.
- Trust wide Schwartz round programme.

The strategy is reviewed on a regular basis by the Trust End of Life care committee. This is chaired by the Director of Patient Experience and reports into the Trust Quality Committee, a sub-committee of the Trust Board.

The strategy is currently being updated using patient feedback, latest end of life care guidance, the new Trust Clinical Strategy and the new NHS 10 -year plan with the aim of being launched in August 2019.

The Pembridge business plan

The Pembridge has its own business plan which includes a number of aspirations for the service over the next 3 years. This has led to the development of a communications plan leading to improved communication with relatives and carers. Current work is looking to redesign the Pembridge Day Hospice to include a wider range of clinical treatments.

Recent service developments

The Pembridge Hospice has recently implemented the SystemOne IT system which gives them intra-operability with primary care and the service has begun to implement the Outcomes Assessment and Complexity Collaborative (OACC) suit of clinical outcome measures across ward, community and day hospice. This enables more patient-focussed clinical interventions and provides a real time measure of clinical effectiveness.

St John's Hospice

Overview

St John's Hospice is part of the Hospital of St John & St Elizabeth. The hospital has a charitable status. The Hospice Director sits on the hospital board.

The hospital board oversees the operation of the Hospital of St John and St Elizabeth and St John's Hospice. By volume, the main business of the board is the operation of the hospital where they are about to embark on a huge project to rebuild the operating theatres at an expected cost of approximately £40m.

St John's Hospice employs 72 staff which represents 64.33 FTE's. It also has 150 volunteers which help with patient care on the inpatient unit and in the retail shops. At any-one time it is supporting approximately 850 patients.

They are the only hospice in the tri-borough area that run a Hospice@Home service. This is a service which delivers practical care and support in the last days of life to people at home. They also are the only hospice to run a lymphoedema service in all three boroughs.

The largest element of the Hospice@Home workload is terminal care, with the service also providing respite care, admission avoidance and facilitated discharge. The nurse co-ordinators work closely with the Continuing Health Care (CHC) team and are occasionally asked to assess a patient, to establish the level of need.

The Hospice@Home service provides care for up to two weeks, usually as day care, night care or both. Packages average six days in duration, and average 105 hours in total. Hours of care delivered in 2018 were 21,896, a 19% increase on 2017 (18,394).

Finances, Contracts and Monitoring.

For 2018, the Hospice had annual running costs of £6.9m. The revenue to cover this came from NHS contracts (£2.8m), fundraising (£2.3m) and the surplus made from the Hospital of St John and St Elizabeth (£1.8m).

Accounts submitted to the Charity Commission for the year to 31st December 2017 showed an increase of income to the hospital of 1.2% to £58.2m; and an increase in operating costs of 2.6% to £55.7m. Free reserves are £6.8m and their operating surplus for the year was £2.5m.

St John's are commissioned on a standard NHS contract and performance is measured against bed days, new patients to the community service and day care attendances. The bulk of their specialist palliative care activity is for Central London CCG, followed by West London CCG. They deliver services for patients in Brent, Camden and Islington CCGs with NHS contracts valued at £700k annually.

In total, St John's receives £2.8m from their NHS contracts which represents 46% of their care costs and 40% of their total costs. There has been no uplift in the NHS contribution over the past few

years, despite rising costs. They meet their contractual expectations but have capacity to substantially increase their inpatient care as the unit is commissioned for and operated at 63% capacity for 2017-18.

Strategic Plan and Progress

The hospital has published a strategic business plan for 2018-2020. Within the document it has 8 actions required to be completed by the hospice in 2018-2019

- Augment Hospice@Home services.
- Develop outpatient clinics for community/day care patients.
- Achieve growth year on year in numbers of patients.
- Increase uptake of feedback methods for patients and families.
- Demonstrate full compliance with relevant quality standards.
- Perform within annual budgets for revenue and expenditure.
- Develop educational programmes for local health professionals raising awareness of the hospice.

Recent Service Developments

St John's have developed joint working with Imperial College Healthcare NHS Trust for patients with COPD and heart failure, attending a regular multi-disciplinary team meeting with the respiratory and heart failure teams.

The hospice clinical staff have regular contact with the Butterworth Centre, a care home located on the Hospital site.

Forrester Court care home is supported by a Clinical Nurse Specialist in the Specialist Community Palliative Care Team, who attends a monthly multi-disciplinary team meeting with care home staff and representatives from primary care.

The Royal Trinity Hospice

Overview

Royal Trinity Hospice (RTH) is an independent charitable hospice founded over 125 years ago with accounts submitted to the Charity Commission. There is a board of trustees governing the hospice whose sole purpose is the improvement in palliative and end of life care. RTH supports over 700 people at any-one time across central and south west London. They service four other boroughs as well as the tri-boroughs. RTH employs 256 staff and has a well-developed 'army' of volunteers who assist in almost every area of the hospice.

Finances, Contracts and Monitoring

RTH have a standard NHS contract in a multi CCG alliance as they service not only the tri-borough CCG's but Wandsworth, Lambeth, Merton and Richmond CCG's. Lambeth is the lead commissioner and achievement on the contract activity is based on bed days, numbers of patients seen by the community palliative care nursing team and outpatient attendances.

In 2017-8 they received £718,816 in funding from the tri-borough CCG's plus a further £227,607, which is a historical sum of money given over ten years ago by central government, originally via the cancer networks to hospices to help them make improvements in line with the End of Life Strategy of 2008.

There has been no uplift to the NHS contribution for many years, despite rising costs, and the NHS core contract contributes only 18% of the hospices running costs. The RTH has to raise £9.5 million each year to close the gap between NHS funding and the cost of providing services.

Forty five percent of independent hospices are reporting that expenditure is now exceeding income, with Royal Trinity Hospice included.

In 2017-18 revenues declined from £12.4m to £11.9 m, due to a decline in fundraised income, although this was partially offset by increased retail income. Expenditure increased slightly by 1.3% to £12.5m mainly due to a 1% salary increase and an increase in retail property costs. The deficit for the year was £0.635m before depreciation. Year-end net assets were £20.9m and year on investment assets were £5.9m, which would cover five months of operating costs at 2017-8.

Strategic Plan and Progress

A strategic plan for 2018-21, has been developed, which aims to:

- Develop impact reporting to identify strengths and weakness in the service;
- Ensure sustainability of their services; and
- Develop their community services to enable the hospice to see 30% more people in three years.

Royal Trinity Hospice has already made considerable progress with their strategy. They have developed an impact report, visit their website www.royaltrinityhospice.london

The published data informs us that 2351 patients were supported by Royal Trinity last year:

- 58% had cancer, 42% did not.
- 93% had an advance care plan, 69% died in the place of their choice and only 1 in 4 people died in hospital.
- 94% of patients seen reported an improvement in their pain.

Ensuring sustainability means increasing fundraising and retail income year on year to support the growth in patient services. The growth strategy has seen four new shops open during 2018/9 with more to come in future years, and an increase in fundraising targets over the next few years.

In developing their community services, they have re organised their model of care in West London CCG, with a 'team around the patient' model of shared competencies. The model is allowing for more proactive and efficient care.

Recent Service Developments

Royal Trinity Hospice have modernised their traditional day care services. The primary service intervention is therapeutic with a range of drop in activities alongside rehabilitative palliative care, enabling them to spread their resource in a cost-effective focussed way. A dementia community nursing service is provided across the whole catchment area. A converted inpatient bay has become dementia friendly, allowing the hospice to offer respite care and all staff have been trained in dementia awareness enabling them to be 'dementia friends.' They have one independent nurse prescriber and plan to develop more. Since 2015, a successful co-ordination service is provided in Wandsworth CCG (see appendix H). The hospice is also pioneering the use of 'Virtual Reality' for patients, through a research study examining its potential therapeutic effectiveness.

Central North West London NHS Foundation trust (CNWL) Palliative Care service in North East Westminster

There is also a small area of North East Westminster whose community palliative care services are provided by CNWL and commissioned by Camden CCG. The approach to the commissioning of palliative care across North Westminster boroughs is a product of legacy commissioning. The service covers 5 GP practices.

The CNWL team is part of a large established community focussed service and is working proactively as part of the North Central STP to deliver on the last phase of life plan (Appendix I). They have a quality improvement plan across a range of markers and offer a high volume of education. An end of life strategic plan is about to be ratified by CNWL which amongst other things will see an increase in the educational offering to health care professionals working in the tri-boroughs.

Many aspects of the last phase of life plan parallel the recommendations within this review. This is the only service which currently delivers a 24- hour advice and visiting service to patients in their own residence.

Services Provided by the Palliative Care Services

	St Johns Hospice	Royal Trinity Hospice	The Pembridge Palliative Care Service	CNWL palliative care team
In-Patient beds	18 beds 24/7 Admissions	28 beds 24/7 admissions	13 beds 24/7 admissions	No Hospice inpatient beds
Day hospice	10-4, 4 days a week	Traditional day care has developed into flexible outpatient, therapeutic and social activities available 9-5pm , 5 days a week	10-4 ,4 days a week	No day care facilities
Community palliative care	Mon-Friday 9-5pm with one CNS working at the weekend 9-5pm	Multi professional team around the patient with a 7 days a week visiting service led by the CNS's.	Mon-Friday 9-5pm with one CNS working at the weekend 9-5pm.	Community services provided Mon-Fri 9-5pm with clinical community visits available if needed outside of these hours
Out of hours advice	Managed through the ward nurses after 5pm. Back up doctor is the RMO on for the hospital. Second on is a palliative care consultant second on call	24/7 specialist clinical /medical advice. A CNS is on the late shift at the hospice until 8pm and then available for telephone advice 8pm-9am. This is supported by two on call doctors: a first on call specialist registrar, and a second on call medical consultant, all available to speak to health care professionals and patients/carers as required.	Usually managed by the ward nurses after 5pm with back up advice from the shared rota with St Johns. Currently a Cis on call to give advice and the medical rota is shared with 3 other consultants from different providers.	Full telephone advice accessible through an 'on call' service' via the hospital switchboard from 5pm until 9am, 7 days a week.
Hospice @ Home	Small service that sometimes bridges CHC packages of care. Not available in H&F	No	No	No

Bereavement support	yes	yes	yes	Bereavement support is delivered via the team social workers
Lymphoedema service	Yes	No	No	No

Figure 3: Provision of services

Recommendations:

- There is one commissioner for end of life care in the tri-borough CCGs.
- That the CCG’s address the inequity of current funding arrangements for hospices.
- That service specifications and contracts are standardised.
- That the NHS meets the cost of all core community palliative care services.
- Response times from specialist level services should be in line with the degree of urgency of patient need and measured.
- Measured activity should not solely be based on direct face to face contact with the specialist level provider but their sphere of influence with others. For example, a specialist level practitioner may advise on the management of patients whose service is being delivered by others.
- The service provision should be based on the patients GP and not where the patient resides.
- User feedback using a validated tool should become a routine part of outcome measures e.g. Voices for Hospices (which includes non-bedded service) The CCG’s may want to develop a mechanism for feedback for the whole of their integrated care programmes in which case the specialist level palliative care should be incorporated into this.

Specialist Palliative Care Activity

Available data

The review found that data collection for the specialist palliative care services was inconsistent and therefore benchmarking the activity and performance was difficult. Royal Trinity were not able to breakdown their activity into working hours and 'out of hours.' Data on bereavement services and therapy services has been omitted in this report due to the lack of accurate data. Data on the out of hours advice line activity is also missing as none of the providers collect any data in this area. The review was also unable to see data on the different aspects of the non-bedded services at the Royal Trinity, as the data was all recorded under 'home care activity.'

At the time of this report, no data was available for the CNWL service based at St Pancras Hospital. However, the data available shows:

- The reach of the current services impacts on 48% of expected deaths. It is suggested that 60-75% of dying people could benefit from palliative care²⁵.
- The numbers of patients seen with a non-cancer diagnosis is increasing each year, currently about 30%.
- 23% more people die outside of the acute sector if a palliative care service is involved.
- 458 people were admitted to a hospice bed out of 2,222 expected deaths. Admissions are possible out of hours but only 21 people were admitted to an inpatient bed at this time. (This excludes the RTH which is unable to provide data on out of hours admissions).
- Utilization of available inpatient beds was low in two settings; PH only had a 67% occupancy and SJH 63%. However, SJH met its contractual obligations. The PH have a block contract and the percentage occupancy and target for admissions is not stipulated.
- Insufficient doctor or nurse activity in outpatient clinics, which are a cost-effective setting to assess a patient.
- In SJH and PH, few new patients' access the service (47 for the 2017-8) and both are still running traditional day services rather than a drop in, goal focussed and rehabilitative approach service enabling many more people to benefit from palliative care.
- The length of stay in the hospice beds is amongst the highest in London. 16-17.8 days with a London Hospice average of 14.6 days (Appendix K). This may reflect the paucity of care home beds.
- Hospice@Home receives outstanding feedback for the quality of their care but are only involved in a 3% of expected deaths in the boroughs. Developing this across the boroughs is likely to be prohibitively expensive and similar to the cost of a bed in a hospice or hospital.

Inpatient Hospice Bed Usage

It is generally accepted that hospice beds should be used for patients who have complex and intractable problems that are unable to be managed at home. This should include patients with severe psychological distress but not overt mental health problems as most hospices are not structured to have formal links with mental health services. RTH do have arrangements for psychiatric assessment and management of patients with mental health problems.

All hospices should have the facility to manage complex pain with more acute interventions such as intrathecal blocks and epidural catheters. All the tri-borough hospices are able to seek opinions from chronic pain specialists and manage intrathecal blocks and epidural catheters. The Government's ambition to deliver preferred place of death Commissioning for Quality and Innovation national goals, 'CQUIN's', has influenced hospice admissions, to admit patients whose preference is to die in a hospice, but who do not necessarily require specialist palliative care.

Bed costs

The price for a bed-day within the tri-borough CCGs are:

- Hospice - £750
- Hospital - £411 (based on 800 NW London admissions, April 2017-December 2018, average Length of Stay 13 days)
- Residential nursing home – £111-£301 (CHC contracts)
- National data for final admissions shows that 32% die after a stay of 0-3 days, 18% after a stay of 4-7 days and 50% after a stay of 8 days or longer.^{26 27 28}

The length of stay in a hospice bed commissioned by the tri-borough CCGs is higher than the London average and slightly more people die in a hospice bed than in other London boroughs. In 2017-8, there were 458 hospice admissions from the tri-borough CCGs and 213 deaths (West London CCG - 84, H&F CCG - 50, Central London CCG - 79).

Hospice beds are an expensive place to die compared to other settings. Although the cost to the NHS is heavily subsidised in the independent charitable hospices, hospice beds should be thought of as "critical care beds" for the highly complex rather than a place to choose to die.

It is unlikely that there will be an increased need for 'critical care' inpatient beds for people who have highly complex symptoms. Given the low occupancy of PH and SJH there is probably enough capacity in the system for the tri-boroughs to operate with less specialist palliative care beds (Appendix L). Indeed, the system has been managing without the 13 beds at PH since October and as far as we can tell the majority of patients requiring admission have been redirected to other units where there has been spare capacity. As far as we are aware, there has only been one patient who refused an inpatient admission to St Luke's in Harrow because of distance.

Only RTH has kept data on admissions requested from the tri-boroughs that were not fulfilled which was 15 patients for the 2017-18 year but even with this data we do not know the reason for non-admission. The hospitals report instances of patients who died waiting for a hospice bed but unfortunately there is no data to demonstrate this.

Every hospice has reported difficulties in discharging people who need a Continuing Healthcare care home bed. Given the low ratio of care home beds to the over 75 age group in the tri boroughs, this is not surprising. This in turn increases the average length of stay in a hospice bed. To ensure robustness of this assessment it will be important to understand the impact of the long stay patients and the reasons why they cannot be transferred out of an inpatient bed. It appears that there is a problem with patient flow at the correct level of acuity. It seems likely that more CHC fast track beds are needed rather than specialist palliative care beds.

The reviewers assessment is that it is there could be a reduction in specialist palliative care beds if :

- There were more CHC beds in the system.
- The hospices ensured that the admissions truly required a 'critical care' hospice bed.
- The numbers of patients who require an inpatient 'critical' hospice care bed is approximately the same as the numbers of 2017-8 (485)
- Hospices ensured that their discharge procedures worked to NHS guidelines
- The model of specialist palliative care in the community improved in line with the recommendations.
- The number of beds that could be decommissioned is outlined in Appendix L, and is based on the assumptions as outlined.

Recommendations:

- Reduce the number of commissioned beds/bed day activity (see appendix L for modelling and assumptions).
- Reinvest cost savings to improve community palliative care service as outlined.
- Care is co-ordinated from a central hub that operates from 8am to 8pm 7 days a week involving quick and efficient access to care, advice and signposting. This will increase the reach and influence of the specialist services, particularly to those with multiple-co-morbidities in their last phase of life. Included in the co-ordination/casement management centre are:
 - A clinical triage and assessment with competent staff of sufficient seniority and authority to get the right care to the right person at the right time with the right service. The district nursing services should be firmly linked into the care co-ordination centre/case management centre.
 - Referrals for hospice in-patient care should also be directed to the care co-ordination/case management centre and forwarded to the appropriate unit, or have a shared referral 'box.' This will make it easier for referrers both in the acute sector and primary care.
 - The care co-ordination centre/case management centre will need to provide a rapid response service.
 - Consultant doctors and nurses should be part of the case management/care co-ordination centre both in an advisory capacity and for urgent assessments for people at home/care home. Joint visits with the GP are to be encouraged.
 - Community specialist palliative care provision should be mostly targeted at short term episodic interventions. The majority of their work should be aimed at coaching, training and empowering others. They should take responsibility for case management to recognize when their involvement is needed. This will ensure that the reach and influence of the specialist palliative care provider is greater.
 - There should be a joint audit between the CCG and the hospices to better understand the reasons for the long inpatient length of stay and the issues the hospices are raising re transfer to a care home setting.
 - The CCGs should review their provision of CHC funded beds.
 - Hospices should review their bed provision to ensure admissions are for those with complex and intractable problems. They may wish to develop a mixed provision with appropriate resourcing and pricing.
 - Reduce the number of beds that are not being utilised, reinvest the money into the community provision, which will in turn further reduce the need for as many beds over time.
 - The hospices work with the CCG's to ensure there is a common understanding of the cost of a bed day and agree a common model for funding inpatient care.
 - For Commissioners and Hospice Providers to develop a service specification and pricing mechanism via a tariff to ensure effective use of inpatient beds
 - Work should be undertaken with the local authority to commission a lead provider to integrate and standardize the many small bereavement services that exist in the boroughs and a new model developed.

Specialist Palliative Care Medical Provision

Royal Trinity Hospice

Establishment	IPU	Community/OP/day care
Medical Consultants	1.3	1.05
StR's/speciality Drs	2.0	0.7
Drs in training	3.2	0
Total	6.5	1.75

St Johns Hospice

Establishment	IPU	Community/OP/day care
Medical Consultants (employed by CLCH)	1.2	1.0
StR's /speciality Drs	2.6	0
Drs in training	0.45	0
Total	4.25	1.0

Pembridge Palliative Care Services

Establishment	IPU	Community/OP/day care
Medical Consultants	1.0	0.8
StR's /speciality Drs	3.0	0
Drs in training	0.5	0.5
Total	4.5	1.3

Figure 4.

The table above describes the breakdown of where the palliative care doctors are primarily based. For an inpatient bed, the doctor has primary responsibility for the clinical management; in the community this sits with the GP. Doctors in training are always likely to need their primary working practice to be in an inpatient setting as it is the place that they are able to get to see more patients in a shorter space of time. However, there are up to twenty times more patients under the community palliative care team than in an inpatient bed at any one time.

Recommendations:

- The hospices review the balance of their medical work plans and move resource to work with the care system in the community. They could consider some of the bed management to be led by senior nurses.
- When recruiting, consideration should be given to the balance of medical staff with some consultants, doctors in training to be palliative care consultants, speciality doctors as well as GP's with a special interest in palliative care.
- Medical staff in palliative care that deliver to the tri-borough CCGs, have an agreed mechanism for cross cover 24/7 to ensure service resilience.

Stakeholder data & themes

Data collection

The stakeholder feedback was collected in the following ways.

- Face to face or telephone interviews were held with more than 50 key professionals working in the provision of specialist palliative care services.
- A number of focus groups were held with patients, carers and patient representatives. A public 'Call for Evidence' which received 101 responses via an online survey (51 public- mostly informal carers and families, and 50 professionals/staff from the care system). Qualitative and quantitative data was captured
- 11 further submissions were received from individuals or larger national or local organisations.

Focus group data is in Appendix M. It is evident that the current hospice patients and their carer's are very satisfied with the services they are receiving which was largely day care. The BME user group who were not currently accessing palliative care services described feeling 'lost' in the health care arena and the terms 'hospice' and 'palliative care' were confusing. This is important feedback and better data needs to be obtained on the uptake of palliative care services from marginalised or 'hard to reach' groups.

Stakeholder themes

The key themes across all groups

<p>Patients, families and carers report high satisfaction rates once they start receiving a specialist palliative care service.</p>	<p>There are variations in services, contracts and performance across all providers.</p>	<p>There is no one commissioner with oversight of all specialist palliative care provision across the tri-borough.</p>	<p>The NHS contribution towards the care costs varies across providers. (range 18%-100%)</p>
<p>There is a variation across providers in the ratio of specialist palliative care nurses in the community per head of population.</p>	<p>The involvement of the community based palliative care teams significantly improves the likelihood of dying outside the hospital setting which is what patients say they want.</p>	<p>The palliative care services in the tri-borough reach approximately 48% of patients who have an expected death.</p>	<p>Getting a rapid face to face assessment from the specialist palliative care provider in the community is problematic.</p>
<p>Access to a senior a specialist palliative care clinician to aid decision making for a GP or community nurse can be problematic and inconsistent.</p>	<p>The Community Independence Service (Rapid Response team) are regularly called to patients who on initial assessment are in need of end of life care.</p>	<p>The model of daycare varies: Traditional model by St Johns and Pembridge saw a 47 new patients in 17/18. Trinity has a modernised day care and rehabilitative approach.</p>	<p>District Nursing services feel aggrieved that the Specialist Palliative Care services see themselves as advisory and not interventionist.</p>
<p>Specialist Palliative Care nurses perceive District Nursing to be task orientated, not holistic and personalised.</p>	<p>74% of the public who responded to the online survey reported poor co-ordination and communication between services for people at the end of life.</p>	<p>The percentage of deaths at home is higher in all 3 boroughs(28.2%) than London (23.8% or England (23.5%)</p>	<p>Deaths in hospital for the boroughs(48.9%) are higher than England(46.9%)but lower than London(52.8%)</p>
<p>Referrers who interface with more than one provider for inpatient care have a perception that hospice A is better able to cope with complexity than hospice B and refer accordingly.</p>	<p>The specialist palliative care services different IT systems that have no interoperability with primary care or the hospitals (exception Pembridge)</p>	<p>Based on the number of inpatient bed days available across the tri-borough, there is capacity in the system to admit more patients or close some beds.</p>	<p>Length of stay is above the London average of 14.6 days: <ul style="list-style-type: none"> • St Johns Hospice: 17.8 days • Pembridge inpatient unit: 17.8 days • Royal Trinity: 16 days </p>
<p>There is a lower ratio of nursing care home beds in the tri-borough compared to the London region which may impact on the length of stay.</p>	<p>The palliative care services still predominantly deliver care to people with a cancer diagnosis but this is steadily changing. (Average 70/30)</p>	<p>The balance of palliative care medical time is heavily weighted to inpatient beds and not the community</p>	<p>The occupancy of two of the three units is low: 63% St Johns Hospice - 67% CLCH Pembridge Inpatient Unit (2017-8 figures)</p>

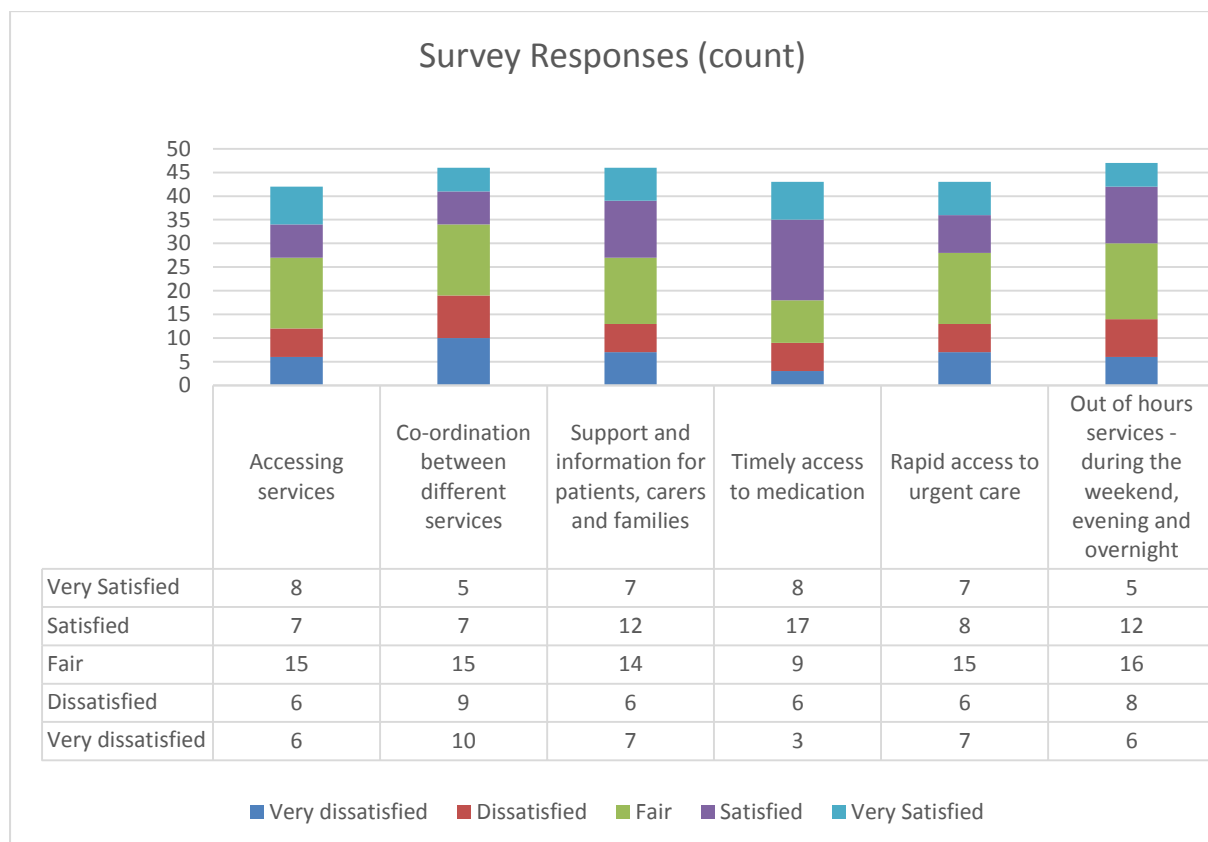
The analysis of the survey monkey data is below. The data is split between the professionals which is largely health and social care staff and the public which is largely patients, families and informal

	Numbers of respondents	% who were very satisfied or satisfied
Accessing Services	42	36%
Co-ordination & communication between services	46	26%
Support and information	46	41%
Timely access to medication	43	58%
Rapid access to urgent care	43	34%
Access to services out of hours	47	36%

carers.

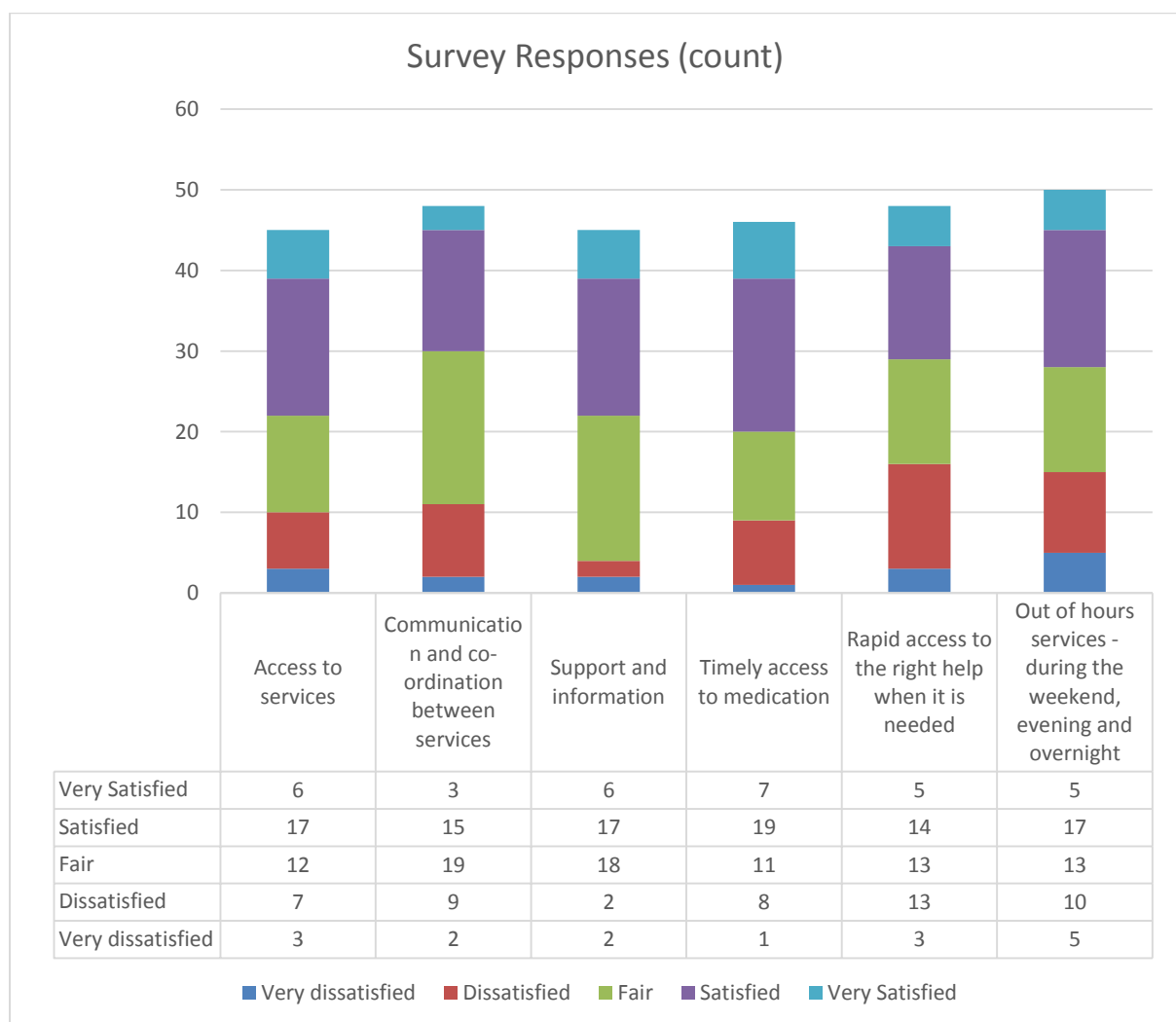
The vast majority of the feedback from both groups is strongly correlated. The least satisfied are the public where only 26% rate the co-ordination of care and communication between professionals as satisfied or highly satisfied. On every measure there is much room for improvement.

Survey Monkey Responses from the public



Responses from Professionals & staff

	Numbers of respondents	% who were very satisfied or satisfied
Accessing Services	45	51%
Co-ordination & communication between services	48	37%
Support and information	45	51%
Timely access to medication	48	39%
Access to services out of hours	50	44%



Online survey comments received relating to the review from the public:

" I didn't know how to access the services we needed."	" I didn't know how to get continuing health care funding."I	" I could have done with a fact sheet on palliative care."	" We were really helped by the care at night."
"Palliative care is hugely underresourced in the tri boroughs"	"The lack of co-ordination between medical and social services is a disgrace."	"Communication between serices needs improving."	"Information is not passed from one service to another."
" I have only good things to say about services I received."	" Everyone was caring and supportive."	"Dealing with different departments was fragmented and frayed."	" closer collaboration would help-the hospital prescribed a medicine we cojuldn't get at home
"Our hospice is closed, we need good doctors and more nurses- it is an exemplorary service."	" We need easier access to pain relief at home."	"palliative care made no difference."	" We needed more care at an earlier satge when the diagnosis was terminal."

A sad, articulate and detailed submission also came in from a recently bereaved carer. The carer described the difficulties that she had accessing the right care at the right time for her husband and experienced services working in silos. The patient needed urgent equipment, a care package, symptom control and a care plan. The carer and patient felt let down by most of the services and no services responded in a timely manner considering the urgency of the situation. Eventually the patient was admitted to a hospice where he received good care and died a few days later. This is a far too familiar story and serves as a 'vignette' of why this review is important.

Feedback from the two Hospice groups:

" I feel safe coming here every week."	" It's a wrap around service and home visits are provided , if needed."	" support for families is excellent."	" Need better cover at the weekends."
" End of life care should be as important as maternity care."	" The hospice helps me navigate the rest of the system."	" They know me well at the hospice."	"It provides me with a support network."
"It's given me a new lease of life."	"They always listen and take my concerns seriously."	" I can get rapid access at the hospice to the right help."	I didn't want to be referred but now I wish it had been earlier."
"The staff are so supportive and reliable."	"Here at the hospice I can easily get sorted."	'It's a strong word but I mean it, I love it here."	" I wish I could come more often."

The future challenges of palliative care

Defining complexity & who requires specialist care

Services have traditionally delivered care to a population of people that were considered to have complex needs. However, there is no standard definition of 'complexity' and in reality, it has been defined by a case mix classification such as disease group, age and physical symptoms.²⁹ This was in practice limited to those with a cancer diagnosis, younger people, alongside a limited number of those presenting with neurological diagnosis e.g. Motor Neurone Disease. There is an urgent need to define what constitutes complexity.

The specialist palliative care model, delivering a one size fits all, gold standard service to a few is no longer fit for purpose. Published research over the last few years has demonstrated similar symptom burden and distress in other disease groups and the multi morbid frail population.³⁰

The trajectories of dying are different in the different groups of people as illustrated in figure 5 and new models of care must take account of this.³¹ Specialist Palliative Care providers need to plan these trajectories in parallel with social care.

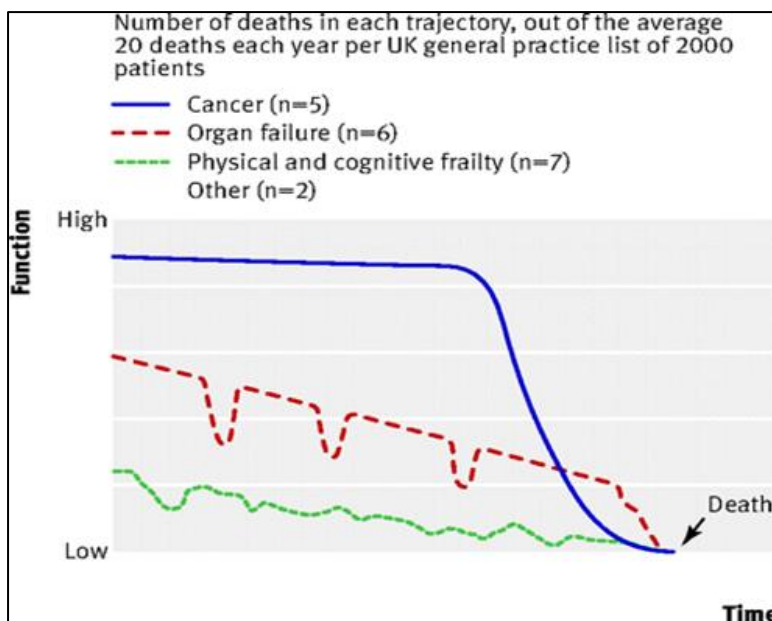


Figure 5

Rapid response

Currently in the tri-borough CCGs the specialist palliative care providers do not see themselves as needing to respond rapidly to urgent situations, the contract for community nursing states that they have up to 24 hours' to respond and so the default position often becomes a referral to the Community Independent Service (CIS). A rapid response service who have a remit to respond within 2 hours or the London Ambulance Service. Neither of whom can currently make a direct referral to all of the specialist palliative care services and most of whom require a referral to come from the GP.

The role of the palliative care nurse specialist

How specialist palliative care services integrate in a meaningful way with mainstream health and social care services is another challenge. Traditionally the clinical nurse specialist (CNS's) has had an expert advisory role within primary and community health care teams. This has led at times to challenges between district nurses and CNS's regarding role and function. District nurses have felt that nurse specialists can be overly precious about their role and are reluctant to be involved in direct hands on patient care should the situation require.

Specialist nurses have also been reluctant to become directly involved in the administration of medication via a syringe driver or for a patient who needs a one off injection. CNS's must take a more interventionalist approach and undertake nursing tasks particularly when with a patient. Palliative care nurses become frustrated when district nurses take a 'task orientated' approach to care and fail to see and address the needs of the whole person.³² Specialist nurses sometimes find district nurses reluctant to take instruction from other nurses and depending on the communication skills and experience of the CNS, this may or may not affect the working relationship and also the care that the patient receives.

How specialist and community nurses work together is fundamental to the delivery of high quality specialist palliative care. Where relations fracture, care is compromised and it is important for both sets of nurses to meet together regularly and discuss patients, to acknowledge both difference in practice and also role overlap and to be honest and open about how to best work together.

CNS's need to be highly competent and train to the level of an advanced practitioner. These roles are experts in clinical practice, facilitate learning, provider leadership and ensure services are based on best practice. The Nursing and Midwifery Council has not yet regulated these roles but it is generally acknowledged in specialist palliative care that the advanced practitioner would need to be qualified in advanced assessment, independent prescribing and have successfully completed masters modules in symptom control and psychological care.

Recommendations:

- Introducing and using the Outcomes complexity and assessment collaborative tool (OACC) in all settings 33.
- The development of a rapid response component to the specialist palliative care services to better respond to the different trajectories of dying.
- To introduce a tri borough wide care plan that includes wishes and preferences of the patient and an escalation treatment plan.
- For specialist community providers to be equipped to respond to the nursing needs of patients if they have a planned or unplanned visit.
- For guidance to be developed to describe how primary care, community nursing and specialist palliative care clinicians work together.
- For specialist palliative care nurses to work with district nurses to improve the skillset and confidence of community nurses.
- For a borough wide agreement to be developed on the responsibilities and skillset of clinical nurses specialists to be developed into advanced nurse practitioners.
- Ensure that when the community nursing services are recommissioned the specification includes a rapid response element.
- Change in operational policies of the specialist palliative care providers to enable anyone to refer to their services.
- Primary care contracts to include monthly multi professional reviews for people at EoL.

Working with social care

Delivering personal care to patients is now considered to be the remit of the social care workforce, which is most commonly commissioned from private domiciliary care agencies. The Cavendish review (2013)³⁴ exposed the major difficulties and challenges for this workforce, poor training and supervision, poor terms and conditions and no established links into health services. The separation of activities of daily living from the work of health care and community nursing is particularly problematic for people coming towards the end of their life and deteriorating. It is during this period that there is a serious need for health and social care to be integrated. If they are not, social care workers don't develop the skills and confidence to manage the deteriorating patient with all the anxieties that this incurs for families.

The range of professionals that may be involved in a person's care are extensive and for the patient and family it is of the essential to their experience for professionals to work effectively together. Silo working of services in this phase of life can have far reaching consequences. Dame Cicely Saunders, the founder of the modern hospice movement said, "How a person dies lives on in the memory of those who are left"³⁵. The professionals involved in care can include the following; GP, community nurse, social care staff, palliative care clinicians, the acute sector, the ambulance service and sometimes mental health clinicians and the ambulance service.

Identification of dying people

This is a challenge and encompasses more complex disease groups other than cancer. Many patients are not identified as reaching the last phase of life, particularly frail older people with multiple co-morbidities and therefore do not have the benefit of assessment and care planning to meet their current and anticipated needs. However, there are now some useful tools to help clinicians identify those at risk of deteriorating and dying. The two most commonly used in the UK are the Supportive and Palliative Care Indicator Tool (SPICT)³⁶ and the Gold Standards Framework prognostic indicator guidance (PIG)³⁷.

Recommendations:

- SPICT is integrated into SystmOne for GP's.
- Integration with Health and Social Care

Mitigate silo working by:

- To set up a tri borough palliative care case management/co-ordination centre with one email address and one phone number
- To invest in IT systems that have interoperability.
- To increase the use of the CMC care plan
- For district nurses to have daily video linkage to the CNS's in the care co-ordination centre to plan the daily work for the patients on their caseload with palliative care needs.

24/7 support

Maintaining people in their own home requires appropriate support to be available 24/7. Out-of-hours palliative care is often provided by 'generalists' with no easy access to professionals with specialist level knowledge. The result is that individuals who contact an out-of-hours doctor are at a greater risk of being transferred to hospital at the end of life. An important study synthesized the

components of a palliative and end of life service in the community that engendered security and confidence in patients and families at home³⁸.

Recommendations:

- The care co-ordination centre operates from 8am-8pm.
- From 8pm-8am advice for patients and families is obtained from the hospice advice lines and for out of hours GP's and community nursing, the on-call doctor is available.
- Rapid accessibility to equipment from the care co-ordination/case management centre.

Care Homes

Nationally 20% of the population and 30% of those aged over 75 die in care homes. 71% of permanent care home residents died in a care home and the number of deaths aged 75 years or older in care homes increased by 28% from 2011-2015³⁹. Care homes are a major provider of end of life care⁴⁰, 80% of care home residents have dementia many also have multiple co morbidities. Goodman (2018) ⁴¹ notes that people usually opt to enter or are admitted to a care home when their needs can no longer be managed in their own home and they are unlikely to benefit from curative treatments.

The NHS has recognized the importance of improving end of life care in care homes⁴² and there are many different models of specialist palliative care services working with care home staff both in education and training, and in assessing the resident's clinical needs.

There are no specific recommendations regarding the training of care home staff in this report as the NW London STP has a programme that it is implementing and a clinical triage service that it has introduced with telephone support from a clinician. Video consultation is also being introduced.

Recommendations:

- The care co-ordination /case management centre makes direct links to work closely with the 111*6 care home initiative
- The CCG's review their provision of nursing care home beds to ensure it is adequate for the population both now and into the future
- Ideally, each nursing care home should have an identified link to a specialist practitioner.

Workforce Challenges

The other major challenge for both medicine and nursing in palliative care is the number of people available to do the job. The ageing workforce in nursing, combined with the lack of nurses is becoming a national crisis with vacancy rates reaching higher than 25% in some areas and the national vacancy rate at 11%.⁴³ The numbers of senior district nurses has fallen by 30% with a reduction of 50% in the last eleven years.⁴⁴ Together with cuts in the social care budget this has reduced the number of available support staff to provide personal care to people in their last days of life.⁴⁵ Macmillan Cancer Support have identified a gap of 3400 CNS's across the UK which they estimate will rise to 7000 by 2030. Alongside of all of this is the lack of standardisation and regulation of the competencies required to function at an advanced practitioner level.

In palliative medicine the headcount of consultants in for the UK was 459 FTE's. In 2015 there were reported to be 53.8 vacancies and 30 new posts in development. Only 40 doctors gained places on the annual specialist training scheme which is inadequate to meet the current and anticipated needs. There are also 58 self-reported retirements due in the next five years.⁴⁶

The 'Call for Evidence' and stakeholder feedback revealed a need for training of community nursing and a need to increase the confidence of some GP's in their management of people in the last phase of life.

Recommendations:

- The development of delegated responsibility in the care system through the use of IT programmes such as the 'e-shift palliative care module', where a senior palliative care clinician supervises a group of care workers via video link.
- Built into service provision and commissioning should be time and resource for the specialist level palliative care providers to train and educate the wider workforce. This should particularly include the social care workforce in domiciliary care and care homes.
- Measures are developed for the delivery of education and training.

Dying of or with Dementia or Advanced frailty

Dementia/advanced frailty has emerged as a key issue for hospices as they consider their strategic direction for the future. Dementia is one of the biggest public health challenges and people dying of dementia often receive the poorest care of our population.⁴⁷ For people with advanced dementia acute hospital admissions are distressing, inappropriate and expensive. The length of stay is longer, and a person is four times more likely to die during an admission than anyone else. Most admissions are for infections, which could be treated in a care home.⁴⁸

Palliative care services are now beginning to embrace the needs of people with advanced dementia and taking the opportunity to work closely with both statutory and other voluntary sector organisations such as the Alzheimer's society and Admiral Nursing. Guidelines for services have been produced.⁴⁹

Recommendations:

- To invest in an advance care planning programme in memory clinics as it is important to capture the patient's wishes and preferences at an early stage.
- The rapid response part of the care co-ordination/case management centre will be able to respond to the sudden deterioration of this group and prevent inappropriate hospital admissions.
- Subcutaneous fluids should be available in the community and not require a hospital admission.

Continuing Healthcare (CHC) in the context of the fast track process

CHC is the name given to a package of care which is arranged and funded solely by the NHS for individuals outside of hospital who have ongoing health needs. Packages of care usually involve care worker support in the patient's home or the payment of care in a care home. NHS CHC is free unlike

care provided by local authorities for whom a financial charge may be made depending on your income and savings.

The tri-borough CCGs work together to administrate this contract with 12-16 care agencies to deliver this care. These care workers are an enormously important part of the patients experience of care at the end of life. The possibility of specialist providers interfacing, coaching and training these care workers is likely to have a big impact on the patient experience and the confidence of the family to manage the care. The CHC team also organise night 'drop in' services from their contracted agencies to patients if this is needed as part of the care package. Most of the London boroughs have contracts with Marie Curie whose traditional night service is care from 10pm-7pm, usually in the patients last few days of life. The tri-boroughs purchase this occasionally on a spot purchase basis.

In an audit from 1st April-August 31st 2018, 101 packages of care from the tri-borough CCGs were accepted for CHC funding under the fast track process. This process is to meet the needs of those who are rapidly deteriorating and entering the terminal stage of life. Of those accepted, 64% were still alive 3 months later. This implies that either the information on the application was not correct or there was not enough scrutiny of the application.

Recommendations:

- To move the fast track brokerage part of the CHC service into the care co-ordination centre to enable palliative care clinicians to help with difficult decision making and to build a relationship between palliative care services and the care agencies to impact positively on practice.
- To develop a small team of senior care workers as part of the care co-ordination rapid response service who will help to coach and empower the domiciliary care staff and bridge care packages that the agency is having difficulty mobilising quickly.
- To review the operation and expenditure of the continuing health care team and the contracts for care home provision.

Modernising Palliative Day Care

The most notable changes in the care of the dying, apart from the development of clinical co-ordination centres with advisory hubs and rapid response services, has been in the reshaping of day care services with a rehabilitation approach. Traditionally patients attended for whole days and had access to a huge range of both social and therapeutic activities. Patients often attended for months or years. Whilst there was no doubt that the day care services were of a very high standard, only a small number of patients could access them, leading to gross inequalities. Access was usually based on patient choice rather than a specific need that required an intervention.

A model of rehabilitative palliative care has been developed, defined as:

"Rehabilitative palliative care is a paradigm which integrates rehabilitation, enablement, self-management and self-care into the holistic model of palliative care. It is an interdisciplinary approach in which all members of the team, including nurses, doctors, psychosocial practitioners and allied health professionals, work collaboratively with the patient, their relatives and carers to support them to achieve their personal goals and priorities.

Rehabilitative palliative care aims to optimise people's function and wellbeing and to enable them to live as independently and fully as possible, with choice and autonomy, within the limitations of advancing illness.

It is an approach that empowers people to adapt to their new state of being with dignity and provides an active support system to help them anticipate and cope constructively with losses resulting from deteriorating health.

Rehabilitative palliative care supports people to live fully until they die." ⁵⁰

Hospices are reforming their day care services taking this approach. Many more patients attend for a specific intervention rather than the whole day. Interventions such as circuit training or management of fatigue and breathlessness are proving popular with proven positive impact of increased mobility, confidence and hope under the guidance of physiotherapists. Many of these activities take place in groups, which both makes them more cost effective and enables patients to get the benefit of meeting other people in similar situations. Many more patients, particularly those with non-malignant conditions are accessing rehabilitative palliative care and hospices are becoming more efficient in spreading their resources.⁵¹

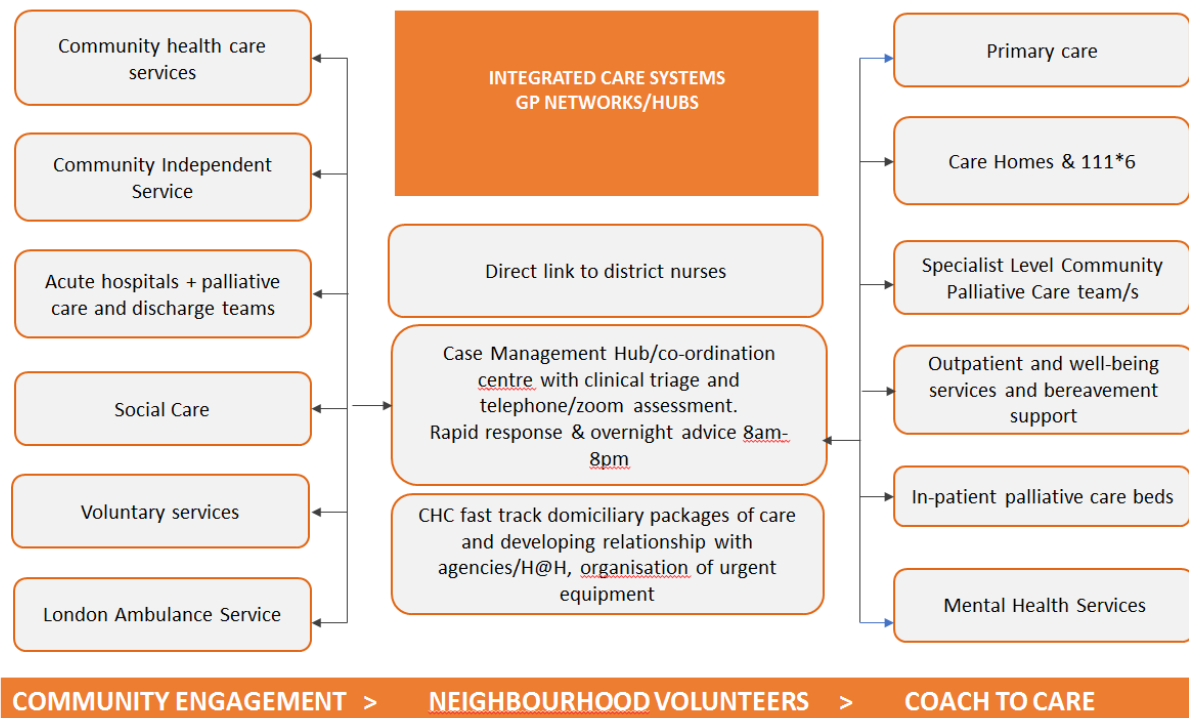
The End of Life Intelligence Network published a Palliative Care Set Clinical Data Set Evaluation Report⁵². It concludes that the use of a suite of outcome measures will drive up quality and consistency of services and help with an understanding of complexity.

Recommendations:

Commission new community-based palliative rehabilitation and health and well-being services to replace traditional day care. Working collaboratively with the voluntary sector, this should also be built into the service specifications.

Recommended model of care

Recommended Model and commissioning options to deliver the recommendations identified:



Overarching Recommendation by Penny Hansford Independent Strategic Reviewer

In conducting this review it has become clear that the three major challenges for the CCG's commissioning services are:-

- inequity of specialist palliative care service provision in the three boroughs
- inequity of access to the services, with only 48% of people who have an expected death having any contact with community palliative care services
- inequity of funding arrangements for the services from the CCG's which ranges from 18-100%

Once in contact with a specialist palliative care service patients and families report high levels of satisfaction.

In order to significantly improve the specialist community service I have suggested a 8am-8pm palliative care hub with skilled clinicians that can ensure patients get the right repose by the right person at the right time. The hub will also have a rapid response service. I have also recommended that the community services are retendered with a lead provider model to enable better co-ordination and accountability.

I am also recommending a reduction in specialist palliative care beds. These are not currently fully utilised. Bed modelling in appendix L has demonstrated that there is some capacity in the system and that more could be created by extra provision of continuing healthcare beds. Since the Pembridge Hospice inpatient unit has been closed the majority of patients have been successfully admitted to surrounding hospices. This, combined with the block contracting arrangement that the CCG's have with CLCH who manage the Pembridge Hospice leads me to recommend that the Pembridge inpatient unit is decommissioned and the monies used to purchase provision in other local hospices and in the re tendering of enhanced community services.

Commissioning options

Option One (Recommended option)

Tender a new community service with one lead provider for the specialist palliative care services, to provide an 8am-8pm co-ordination/case management centre as in the above diagram. Out-patient, rehabilitation and well-being services should be easily accessible to patients and be located within the boroughs. The Community Model would not preclude subcontracting arrangements. Renegotiate bed- based care with separate providers.

<p>Strengths: This has the greatest potential of all the options of delivering a standardised newly shaped service to meet the recommendations listed above, particularly fair access and equality. As one lead provider 'palliative care' also has the potential to operate as a key player in the integrated care systems. Palliative care services are by nature 'small' with often isolated professionals such as medical consultants. This model would also ensure less vulnerability in the key professions.</p>	<p>Opportunities: To radically change the way the services currently operate, address weaknesses in the current system and move to outcomes-based commissioning. If any bed-based services are re-negotiated it will give an opportunity to use the remaining beds more effectively which is likely to be a cost- effective option whilst still accommodating the current numbers of patients who require a palliative care bed. Create a systems leader to effectively implement change.</p>
<p>Weaknesses: The provider of the in-patient bed services may not be the lead provider of the newly tendered contract for the community meaning the lead provider would have less leverage over the use of the beds.</p>	<p>Threats: This is the highest risk in terms of disruption to current providers and therefore potential loss of charitable funds in the health economy and instability of services.</p>

Option Two

Tender a new service and rationalise and reduce the number of specialist providers to two, with the same service specification and contracts. Written within the specification should be the need for the successful bidders to work in partnership to provide a 24/7 co-ordination/case management centre as in the above diagram. Out-patient, rehabilitation and well-being services should be easily accessible to patients and be located within the boroughs.

<p>Strengths: Having two organisations operating to the same specification will help to standardize services. This model will ensure central co-ordination of services and address weaknesses in the current system of co-ordination, accessibility and rapid response.</p>	<p>Opportunities: To radically change the way the services currently operate, address weaknesses in the current system and move to outcomes-based commissioning. If bed-based services are re-negotiated it will give an opportunity to use the remaining beds more effectively which is likely to be a cost-effective option whilst still accommodating the current numbers of patients who require a palliative care bed.</p>
<p>Weaknesses: Having two providers will be harder to ensure standardization and integration with the new integrated care systems.</p>	<p>Threats: if current bed-based providers are not successful in the tender there may be a lack of palliative care beds. There are currently 4 services in the area and with this model two would cease to exist. The boroughs may lose charitable income if the independent providers were not successful.</p>

Option Three

Tender the services based on one community service per borough with the same service specification with one co-ordination centre/case management centre per borough

<p>Strengths: A potential advantage in Hammersmith & Fulham where social care has formally separated from the other two boroughs. Depending on the emerging integrated care systems if the boroughs re model their services based on one single point of access and case management per borough, this model may facilitate integration rather than hinder it.</p>	<p>Opportunities: Development of relationships and collaboration with health, social care and voluntary providers at a very local level.</p>
<p>Weaknesses: Unlikely to deliver the new model with co-ordination and case management and rapid response as each provider service would be small with no economy of scale. Therefore, the model would be more expensive as a greater number of staff will be needed to be replicated three times. Less likely to deliver equity of both service provision with 3 providers essentially working separately.</p>	<p>Threats: Services would remain fragmented and small unless one provider was successful in all three tenders but the care co-ordination/case management model is unlikely to be realised if there is a need to replicate three times. The potential loss of beds/alignment of bed provision may be problematic.</p>

The preferred option

The reviewer’s rationale for recommending option one, a lead provider in the community is due to the significant transformational change needed in the specialist palliative care services to enable them to use their resources in a different way. Acting in a consultative and training capacity to the wider care system whilst managing a small number of highly complex patients themselves, alongside case management for all expected deaths. Achieving the recommended outcomes for the new model of care will be challenging but most likely achieved with a systems leader ‘driving’ change.

There is also an imperative to become part of the emerging integrated care systems in the boroughs and to provide an equitable service throughout. The reviewer believes this is best achieved by an overall lead provider, accountable for the change needed. The integrated care systems are progressing to different timescales and slightly different models in each CCG and so it has not been possible for the reviewer to make a recommendation on how the palliative care co-ordination centre will integrate, only that it will need to.

The idea of a co-ordination centre, single point of access with extended hours and rapid response was consistent feedback from many of the professionals interviewed and now backed up by the patient, family and friends feedback, 74% of whom rated co-ordination and communication between services fair to very poor and only 26% were satisfied or very satisfied.

Contracting the beds separately to the community contract is a pragmatic approach as the provision of care in this setting requires less change management. The system has been managing with considerably reduced bed days for the last year which has not been problematic as two of the three units have been running at under 70% occupancy. Beds are costly and service only a few people. The reviewer would recommend closing a small number of specialist palliative care beds and

investing the money in getting the community model right. The modelling in Appendix L looks at 3 different scenarios with a potential closure of between 4 and 10 beds. This will improve the quality and experience of care for most people and will further reduce the need for as many beds. The actual number of beds that can be closed will be dependent on a further review of delays in the system for patients who need to be transferred out of a specialist palliative care bed into a CHC fast track bed in a nursing care home.

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